

Open Letter to Parents: Disabled People are the Experts!

Phyllis Rubenfeld

Now that New York City's buses have become increasingly accessible and the sidewalks have more and more curb cuts, large numbers of disabled people can be seen on our streets. Obviously, this is a good thing and it is about time!

We can also see increasing numbers of parents pushing their disabled children around on our newly-accessible streets in "buggies," which are really just the same as the strollers typically used for little children, only bigger, built to accommodate disabled children as old as 16. The parents I have talked to tell me that these buggies are convenient for getting children into and out of accessible buildings and/or the family car, and are therefore preferable to, say, power wheelchairs intended to be controlled by the children using them.

I sometimes wonder how much of parents' stated preference for buggies over power chairs has something to do with the fact that with a buggy, the parent remains firmly in control of every aspect of an excursion - speed, pace, any stops made en route are all entirely up to the parent who is doing the pushing. By contrast, a child using a power chair can go where he or she wants to go, at their own pace and under their own steam, which is the essence of independence. To a 16-year-old, a buggy is bound to seem babyish while a power chair can only look like a ticket to adulthood.

All parents know how hard it is to let their children go. For the parents of disabled children, however, letting go is doubly difficult because the risks seem so much greater that it is tempting to decide that their child is "too" disabled to be able to manage age-appropriate activities like crossing the street or going to the supermarket. The truth, of course, is that disabled children are just like non-disabled children in their desire to be increasingly independent as they grow older and it is a prime responsibility of every parent to make sure that happens.

Unfortunately, agencies and the professionals associated with them all too often endorse paternalistic notions about how disabled children are too fragile or too limited to engage in age-appropriate activities, even agencies with special programs designed to teach children how to cross streets and master other simple acts of daily living. Thus it happens that parents who are already nervous about letting their disabled children go off on their own in power chairs will be encouraged in the over protective attitude by well-meaning, non-disabled professionals who buy into the old stereotype of the disabled as helpless dependents who need to be taken care of.

What gets lost in everybody's anxiety about disabled children is the simple fact that it makes children feel better to be more independent and it makes them feel helpless and weak to be babied. It may be harder for parents to let children control their own excursions by using a power chair, but it is even harder for children who are in their teens to be humiliated by being pushed in a stroller by their parents. Yes, it is easier for the parent, as the sales personnel at the "Buggy Booth" will tell you next time you attend an Expo, but that comes at the expense of the child's self-esteem.

The sad fact of the matter is that public policy tends to be made by non-disabled bureaucrats who see nothing wrong in perpetuating the medical model of disability which holds that disability means something wrong. Whether that wrong needs to be corrected, rehabilitated, or cared for, the bottom line is always added up without taking the self-esteem and the feelings of the disabled person him/herself into account. There are still so few disabled adults represented among the work force that it is difficult for people to see just how independent we can be, which means that today's disabled children must struggle to acquire self-esteem in the vacuum created by an ableist school system and a rehabilitation system based on the medical model.

The challenge for disabled people is to figure out how to get our message across to parents which is that you really should ask us what we need and what helps us get it. And one thing we will tell you is this: it is never too early to start encouraging us to be independent by teaching us how to get around on our own. So forget what you are told about how easy it is to push your disabled older children in buggies.

It may be easier, but it is better to foster self-esteem by allowing them to control their own power chairs. Remember: we really are the experts because we have been there and we know.

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